In the past decade, mental health consumers have increasingly become involved in evaluating the quality of psychiatric care and applying sophisticated data strategies to affect system reform. Through multistakeholder partnerships, they have identified outcome indicators, collaborated in the development of a mental health report card, and designed and conducted consumer self-report surveys on satisfaction and needs and preferences for housing and supports. The formation of multistakeholder assessment teams; the definition of the consumer perspective through focus groups and concept-mapping pilots; and research on coercion, personhood, recovery, and empowerment are key activities of consumers/survivors in the field of evaluation.

HOW CONSUMERS/SURVIVORS
ARE EVALUATING THE QUALITY
OF PSYCHIATRIC CARE

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The growing emphasis in mental health on consumer values, community care, and broadened measurements of outcomes has had major significance for the way quality and performance are measured. In the midst of such changes, perhaps the most far reaching is the reconceptualization of the role of the mental health service recipients. In particular, the radical restructuring of health services from public to private systems of care has created opportunities for partnerships in accountability (Campbell 1996).

Over a decade ago, Prager and Tanaka (1979) reported to the Ohio Department of Mental Health on the results of involving mental health consumers in evaluation. They concluded: "Representing the consumer's perspective on the meaning of mental illness and the correlates of 'getting better', the process of client involvement in evaluation design and implementation is not only realistic and feasible; it is, we feel, a professional necessity whose time is overdue" (p. 51). The compelling belief that people with mental illness can grow beyond their diagnoses to reach out and share their experiences and learn from each other has led to the growing role of mental health consumers

in ensuring quality of care in psychiatric services. More participatory styles of evaluation have emerged (Campbell and Johnson 1995), and consumers have begun to apply sophisticated data and health informatics strategies to public policy debates, peer services, and evaluation.

Clearly, consumer perceptions about effectiveness, satisfaction, and quality of services determine which treatments are sought or complied with and which outcomes are valued. On the other hand, when consumer perceptions are compared with traditional mental health services research and evaluation, incongruities of values and perspective emerge. In a review of the research, Ridgway (1988) found that there appeared to be wide differences between consumers and professionals on the relative importance of treatment goals, identification of problems, barriers to service, and needs and preferences for housing and supports. Qualitative data sources also stand as a robust critique of mental health services delivery systems (Chamberlin 1978; Susko 1991).

It is not surprising that the participation of mental health consumers in defining and measuring quality psychiatric services has tended to precipitate a "kind of turf war over controlling human beings in a landscape that includes an entire array of service options and widely divergent goals and definitions of mental health and quality of life" (Scott 1993, 5). In response, some behavioral health systems of care are shifting toward collaborative research and evaluation practice with their customers. Using a continuous quality improvement model (CQI), they are including consumer self-reports on program quality in performance monitoring. Although such efforts have generally involved the passive use of consumers as survey respondents, the push for quality in service delivery from the perspective of multiple stakeholder groups has also led to the development of many innovative service evaluation approaches that include participation of consumers and family members (Johnson 1996). Methods include the use of multistakeholder evaluation teams (Fricks 1995), consumer focus groups (Abramczyk 1995; Carpinello, Knight, and Jatulis 1992; Midgley et al. 1994), and concept mapping (Trochim, Dumont, and Campbell 1993). Further, the application of the Participatory Action Research model (PAR) in both program evaluation (Leff et al. in press) and national policy (Fenton, Batavia, and Roody 1993) has proved to be a useful guide to evaluation protocols that allow divergent views of different stakeholder groups to be reconciled and core data sets to be developed.

Growing numbers of mental health consumers are taking leadership roles in research and evaluation of public mental health services. They have assessed needs and preferences for housing and supports (Collaborative Support Programs of New Jersey 1991; Ralph and Campbell 1995; Tanzman 1993; Virginia Mental Health Consumer Association 1992), defined outcome measures (Consumer/Survivor Mental Health Research and Policy Work

Group 1992; Trochim, Dumont, and Campbell 1993), and developed indicators for report card efforts (CMHS releases 1996). They have also been active in designing quality assurance assessment tools and surveying recipients on satisfaction with services. Although satisfaction has been generally accepted as an important measure of quality, consumers argue that the lack of consumer perspective in the development of current instruments limits their value. Professionally developed satisfaction instruments tend to measure issues that mental health staff feel are important, rather than those shown by consumer studies to be of major concern. For example, there appears to be a reluctance to ask questions that will capture consumer dissatisfaction (Campbell et al. 1996). Recognizing such problems, administrators and consumers are producing consumer-oriented satisfaction studies (Belcher and Johnson 1996). Of late, a group of professionally trained consumer/survivors organized the Consumer/Survivor Evaluator Consultation Network with support from the Evaluation Center at the Human Services Research Institute (HSRI) to provide technical assistance concerning consumer input in evaluation of psychiatric care (TA Center offers 1996).

The work of consumers in evaluation and outcome assessment has largely gone unnoticed by professional evaluators because little has been published in peer-reviewed journals. Still, when the literature is reviewed, a number of recurring patterns can be identified that relate to the role or authority of consumers/survivors in a services research or evaluation project, and the stage of the project when participation occurs (Midgley et al. 1994). Models of consumer involvement have been categorized and found to have considerable range and variability (Campbell, Ralph, and Glover 1993). The central characteristic of most consumer research is that it is grounded in the values of the consumer movement, and proceeds consensually from a shared vision of what is quality in mental health services, and what should be measured.

Since the beginnings of the self-help movement, consumers have asserted that help is best received when there is reciprocity between help givers and receivers (Chamberlin 1978). The Well-Being Project (Campbell and Schraiber 1989) was a watershed consumer-directed survey research project that defined the meaning and measurement of quality and outcomes of consumer-directed and professional mental health services. Analysis of 500 responses to the consumer-developed instrument established a significant link between clinical and administrative staff attitudes and behaviors and the perceived well-being of consumers that was separate from the sequelae of the disease. The study found that coercion in service delivery deterred consumers from seeking treatment and negatively affected clinical outcomes. Of those interviewed, 47% said that they had avoided traditional mental health services for fear of being involuntarily committed. Consumers judged the quality of

care based on their level of perceived coercion, availability of choices in services and providers, sense of personhood (feeling listened to, validated, and respected by staff), and accessibility to information relevant to their care plan.

As the focus on accountability grew throughout the early 1990s, the Center for Mental Health Services (CMHS), through the Mental Health Statistics Improvement Program (MHSIP), supported consumer research efforts to define and measure outcomes that were meaningful to the recipients of services. In a series of focus group sessions, national consumer leaders began the systematic articulation of outcomes, establishing values as a key factor in determining quality-of-care indicators. According to participants, traditional mental health systems pathologize problems in living, hold low expectations of consumer achievement, are paternalistic, offer a limited range of options, and define anger as symptomatic. The most frequently identified concerns were the threat of involuntary treatments, subtle forms of coercion, lack of respect toward consumers by mental health professionals and providers, and the debilitating side effects of medications. It was observed that researchers fail to ask questions that would capture detrimental effects of treatment and care. Recovery, personhood, well-being, and liberty were identified as the most relevant outcomes for program evaluation (Consumer/Survivor Mental Health Research and Policy Work Group 1992). Continued support from the federal government funded two consumer concept-mapping pilots on outcomes and quality of care indicators (Trochim, Dumont, and Campbell 1993). Concept mapping was selected as the method for inquiry because it is structured and replicable on the one hand and participatory and democratic on the other hand. From the brainstorming, sorting, and ranking sessions, "maps" were generated that identified domains and performance indicators that were similar to the items in the earlier focus group sessions.

Building on these preliminary studies, consumers began to advocate for the inclusion of indicators of recovery and empowerment in performance-monitoring protocols for mental health programs and systems. Until recently, severe mental illness was usually considered to be permanent, requiring life-long treatment. The concept of recovery was first introduced in the writings of consumers/survivors (Deegan 1996; Fisher 1994; Leete 1988). Dialogues between consumers and professionals were conducted to begin to understand the process of healing and recovery, and the dynamics of the therapeutic alliance. There appeared to be general agreement that recovery is an internal, ongoing process requiring adaptation and coping skills, promoted by social supports, empowerment, and some form of spirituality or philosophy that gives hope and meaning to life. How professionals promoted or deterred recovery were identified as important measures of quality in psychiatric care (Beale and Lambric 1995; Blanch et al. 1993).

In Ohio, a consumer-run business was asked by a county mental health board to develop and implement an evaluation strategy to identify strengths and weaknesses in the county mental health system. All of the consumers involved agreed that recovery was important and generated a list of indicators, as well as ways professionals could be evaluated based on their impact on the recovery process—both positive and negative. Results from preliminary interviews pointed to the importance of hope. "Providers can build hope and recovery, or they can dash hope, and exacerbato illness" (Ralph, Lambric, and Steele 1996). Research on empowerment that was conducted on self-help groups was also found to be related to positive changes in perceptions of self, social functioning, decision making, and symptomology (Carpinello, Knight, and Jatulis 1992).

C. Wright Mills (1959) challenged us to use sociological imagination to "grasp what is going on in the world, and to understand what is happening in [ourselves] as minute points of the intersections of biography and history within society" (p. 7). By drawing upon the knowledge of "the outsider within," behavioral health care service delivery systems have a great opportunity to take a quantum leap forward to where individual and system decisions can be made in different but dramatically more effective and humane ways. The culture of the mental health care system—and the roles of its participants—and the engineering of information systems are changing toward that end. To the extent that mental health consumers and professionals embrace the concept that consumer involvement in quality-of-care monitoring is useful, cost-effective, and is a consumer's right, technologies have been developed to facilitate the process.

Adopting the slogan of the South African Disability Movement, "Nothing about me, without me," mental health consumers have moved rapidly to be involved in the design and implementation of quality management in psychiatric systems of care. The growth and acceptance of such partnerships in accountability over the last decade show the potential for progress when researchers and consumers/survivors work together in relationships of mutuality and respect.

REFERENCES

Abramczyk, L. 1995. *Share evaluation: Consumer perspective. South Carolina Americans with Disabilities Act project executive summary.* Columbia: South Carolina Department of Mental Health.

Beale, V., and T. Lambric. 1995. *The recovery concept: Implementation in the mental health system.* A report by the Community Program Advisory Committee. Columbus: Ohio Department of Mental Health.

Belcher, L., and T. Johnson. 1996. Consumer satisfaction surveys in West Virginia. Paper presented at the National Conference on Mental Health Statistics, Washington, DC.

Blanch, A., D. Fisher, W. Tucker, D. Walsh, and J. Chassman. 1993. Consumer-practitioners and psychiatrists share insights about recovery and coping. *Disability Studies Quarterly* 13 (2): 17-20.

Campbell, J. 1996. Toward collaborative mental health outcomes systems. In *New directions in mental health* 71:69-78. San Francisco: Jossey-Bass.

Campbell, J., L. Ho, R. Evenson, and G. Bluebird. 1996. Consumer satisfaction and treatment outcomes. In *Proceedings: Sixth Annual Conference on State Mental Health Agency Services Research and Program Evaluation.* Alexandria, VA: National Association of State Mental Health Program Directors Research Institute.

Campbell, J., and J. R. Johnson. 1995. Struggling to reach common ground. *Behavioral Healthcare Tomorrow* 4 (3): 40, 45-6.

Campbell, J., R. Ralph, and R. Glover. 1993. From lab rat to researcher: The history, models, and policy implications of consumer/survivor involvement in research. In *Proceedings: Fourth Annual Conference on State Mental Health Agency Services Research and Program Evaluation.* Alexandria, VA: National Association of State Mental Health Program Directors Research Institute.

Campbell, J., and R. Schraiber. 1989. *In pursuit of wellness: The Well-Being Project.* Sacramento: California Department of Mental Health.

Carpinello, S., E. Knight, and L. Jatulis. 1992. A study of the meaning of self-help, self-help group processes, and outcomes. In *Proceedings: Third Annual Conference on State Mental Health Agency Services Research and Program Evaluation.* Alexandria, VA: National Association of State Mental Health Program Directors Research Institute.

Chamberlin, J. 1978. *On our own: Patient-controlled alternative to the mental health system.* New York: Hawthorne.

CMHS releases consumer report card for field-testing. 1996. *Mental Health Weekly* 6 (19): 1-2.

Collaborative Support Programs of New Jersey. 1991. *Consumer housing preference results and executive summary.* Freehold: Collaborative Support Programs of New Jersey.

Consumer/Survivor Mental Health Research and Policy Work Group. 1992. *Reports 1, 2, 3.* Fort Lauderdale, FL: The Well-Being Programs, Inc.

Deegan, P. 1996. Recovery as a journey of the heart. *Psychiatric Rehabilitation Journal* 9 (3): 91-7.

Fenton, J., A. Batavia, and D. Roody. 1993. *Proposed policy statement for the National Institute on Disability Rehabilitation Research on Constituency-Oriented Research and Dissemination (CORD).* Washington, DC: National Institute of Disability Rehabilitation Research.

Fisher, D. 1994. Health care reform based on an empowerment model of recovery by people with psychiatric disabilities. *Hospital and Community Psychiatry* 45:913-5.

Fricks, L. 1995. *Georgia evaluation and satisfaction team (GEST) handbook.* Atlanta: Georgia Division of Mental Health, Mental Retardation and Substance Abuse.

Johnson, J. R. 1996. *Critical missing ingredients: The expertise and valued roles of people with psychiatric disabilities.* Dialogue on outcomes. Arlington, VA: National Alliance for the Mentally Ill.

Leete, E. 1988. A consumer perspective on psychosocial treatment. *Psychosocial Rehabilitation Journal* 12 (2): 45-52.

Leff, H., J. Campbell, C. Gagne, and L. Woocher. In press. Evaluating peer providers. In *Consumers as providers in psychiatric rehabilitation: Models, applications, and first person accounts,* edited by C. Mowbray, D. Moxley, C. Jasper, and L. Howell. Columbia, MD: International Association of Psychosocial Rehabilitative Services.

Midgley, J., S. Gilliland, S. Rose, M. Livermore, B. Beckstein, and R. Lemoine. 1994. *Initial development of a consumer-centered outcome monitoring system for mental health services to adults with severe mental illness.* Report to the Louisiana Office of Mental Health. Confident, Inc. Baton Rouge: Louisiana State University Press.

Mills, C. W. 1959. *The sociological imagination.* London: Oxford University Press.

Prager, E., and H. Tanaka. 1979. A client-developed measure (CDM) of self-assessment and change for outpatient mental health services. In *New research in mental health,* 48-51. Columbus: Ohio Department of Mental Health.

Ralph, R., and J. Campbell. 1995. Using a consumer developed housing/supports preference survey as a continuous outcome survey. In *Proceedings: Fifth Annual Conference on State Mental Health Agency Services Research and Program Evaluation.* Alexandria, VA: National Association of State Mental Health Program Directors Research Institute.

Ralph, R., T. Lambric, and R. Steele. 1996. Recovery issues in a consumer developed evaluation of the mental health system. In *Proceedings: Sixth Annual Conference on State Mental Health Agency Services Research and Program Evaluation.* Alexandria, VA: National Association of State Mental Health Program Directors Research Institute.

Ridgway, P. 1988. *The voice of consumers in mental health systems: A call for change.* South Burlington, VT: Center for Community Change through Housing and Support.

Scott, A. 1993. Consumers/survivors reform the system, bringing a "human face" to research. *Resources* 5 (1): 3-6.

Susko, M., ed. 1991. *Cry of the invisible: Writings from the homeless and survivors of psychiatric hospitals.* Baltimore, MD: Conservatory Press.

TA Center offers free consumer consultations. 1996. *Mental Health Report* 20 (7): 57.

Tanzman, B. 1993. An overview of mental health consumers' preferences for housing and support services. *Hospital and Community Psychiatry* 44:450-5.

Trochim, W., J. Dumont, and J. Campbell. 1993. *A report for the state mental health agency profiling system: Mapping mental health outcomes from the perspective of consumers/survivors.* Technical report series. Alexandria, VA: National Association of State Mental Health Program Directors Research Institute.

Virginia Mental Health Consumers Association. 1992. *Commissioners guidance questionnaire survey results.* Richmond: Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services.

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